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ABSTRACT

This paper lists practices recommended by the Council for Exceptional Children's Division for Early Childhood in the area of family participation in early intervention and early childhood special education (EI/ECSE) programs for infants and young children with special needs and their families. An introduction to the quality indicators points out that recommended practice in early intervention includes families as policy makers as well as decision makers on behalf of their children. The introduction lists 31 values and beliefs that underlie the recommended practices, and stresses that family participation represents the creation of a collaborative partnership based on equality, trust, and mutual respect. Fifty recommended practices are then listed, within the categories of: program advising/policy making; staff hiring, training, and evaluation; family-to-family support; intervention; interagency collaboration; legislative issues; advocacy; procedural safeguard development; and leadership training opportunities for parents. (JDD)

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Family Participation

Lisbeth J. Vincent and Julie Ann Beckett

Family participation or involvement in their child's early intervention program has been accepted as both a necessary and a valuable practice since the 1970's. Over the past two decades, families have changed and early intervention has changed (Hanson & Lynch, 1992; Vincent & Salisbury, 1988; Vincent, Salisbury, Strain, McCormick & Tessier, 1990). The passage of PL 99-457 in October 1986 confirmed a commitment to active involvement and participation by families in not only the early intervention porcess of their own child, but also the development of early intervention systems and services from a statewide and local community perspective (Garwood & Sheehan, 1989). Recommended practice in early intervention includes families as policy makers as well as decision makers on behalf of their children.

The definition of family participation which has guided the development of these recommended practices is as follows: families are equal members in, can join together with staff and can take part in all aspects of the early intervention system, including all aspects of their child's care and all levels of decision making.

Values and Beliefs which Underlie the Recommended Practices

The following values and beliefs served as the foundation for the development of the recommended practices.

1. People (families and service providers) are competent and can become more so

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2. People (families and service providers) are doing the best they can given their circumstances

3. Both service providers and the family bring to a relationship their past experiences, personal values and beliefs that provide unique contexts in which to view early intervention services

4. Family is self-defined

5. Cultural/racial/ethnic background is self-defined and must be respected

6. Family participation is self-defined; it can vary along a number of dimension and levels of intensity

7. Partnership is a process

8. Getting started in a partnership requires orientation (e.g., to players, roles, overt and covert agendas, funding sources, rights and responsibilities)

9. Both service providers and parents will need orientation and/or training to work within a collaborative partnership

10. Family participation is essential in all levels of program (e.g., hiring, model planning, implementation, evaluation)

11. In order to achieve participation at all levels, there must be a variety of ways for families to participate (e.g., in program evaluation area family could be interviewed, complete a checklist, participate in a focus group)

12. Cross cultural/racial/ethnic/educational/economic participation and representation that reflect the community is essential

13. Participants/partners must be nonjudgemental

14. Family participation options must be flexible

15. Partners must develop a knowledge and appreciation of relationship building; providers must be aware of group dynamics

16. Collaboration is the model and requires developing a common language

17. Family participation is enhanced when we give families what they ask for

18. Parent/professional partnerships can be enhanced when both members of the partnership are provided with training to enhance their skills

19. Within the field of personnel preparation, service providers and potential service providers need to be adequately prepared to work in partnership with parents

20. The unique knowledge, resources, and experiences of each family must be respected

21. Families provide the primary human attachments and early social relationships for infants

22. Clear and open communication must be established among parents and professionals

23. The family's interaction and decision making styles must be respected

24. Family participation is stronger when families are working with confident, well supported professionals

25. Families know what they need to enhance their development

26. No amount of intervention can take the place of what the family brings to the child

27. Collaboration will take place only when the family is the final decision maker and the team is the implementer of decisions

28. Conflict between partners can be healthy and can be resolved

29. Skills that families develop overtime can enhance a program's effectiveness (e.g., by hiring veteran parents to help new parents and to help staff maintain or enhance their sensitivity)

30. Professionals need a supportive, open, creative work environment

31. Families bring to the partnership knowledge and information that is reliable and valuable

Summary of Validated Items

The items validated as recommended practice include family participation in their child's individual program by sharing information with staff, participation in hiring and evaluation of staff, participation in training professionals and paraprofessionals on a

preservice and inservice basis, participation in state level policy development, and serving as a veteran parent in providing support and information to a new parent. Such acceptance shows the commitment to families achieving equality in the system as decision makers and leaders for their own child and family and for other children and families. Other items reflect a commitment to families having options for their involvement or noninvolvement in different parts of the system (e.g., the family is able to determine the pace of service delivery, family support services are available as requested by the family, and natural community settings are developed as an option for early intervention). There is not one right way to participate; there are as many ways as there are families.

In the Program advising/policy making component, the need to provide financial remuneration to parents for their expertise, time and expenses was supported. Family members' ability to participate in all levels of policy and procedure development was also supported. The need to unscramble the "alphabet soup" which colors our professional language and provide family friendly definitions of terms was also recognized.

In the Staff hiring, training evaluation component, the family's role in staff/program evaluation received acceptance. Involvement in both developing evaluation instruments and formulating conclusions based on the results was recognized. Involvement in the training of new staff and ongoing staff development activities was also supported.

In the Family-to-Family support component, recommended practices include having this type of support as an ongoing part of the early intervention system. The need to link families to natural community supports was highlighted.

In the Intervention component, the family's role in determining the place of service

delivery and the pace of service delivery was recognized. The need to provide options to families and to make the options they develop work was also supported.

In the Interagency collaboration-Meetings, evaluation, implementation component, the need to provide information to families about the "process" so that they can be contributing team members was recognized, as was their role in evaluating our success in interagency collaboration. Using the interagency process to increase typical community settings available for children with special needs was also supported.

In the Legislative issues component, the need for families to receive information about their legal rights and due process in their native language was widely supported. Also recognized was the need to support individual family's decisions about whether to become involved in the political action process.

In the Advocacy component, the need to join our efforts with those of regular early childhood educators and supports was recognized. The family's role in determining what issues should receive the focus of advocacy groups was also supported. Professionals recognized their responsibility to tell families when they could not advocate for issues identified by the family.

In the Procedural safeguard development component, a family's right to choose alternative treatments in non-life threatening situations was supported. Also supported as recommended practice was the use of an independent mediator if program and family are in conflict.

In the Leadership training opportunities for parents component, the need for the early intervention "community" to coordinate its efforts with parent information and training

groups was accepted as recommended practice. Also recommended was the funding of annual, formal leadership training activities for families by the State lead agency and Interagency Coordinating Council for Early Intervention.

Conclusion

Overall, the validation process has confirmed a change in how we as an early intervention community view family participation. We recognize that the involvement of families is more than giving advise about how to interact with/raise their young children with special needs. Rather family participation is the creation of a collaborative partnership based on equality, trust, and mutual respect. Families are truly equals in this partnership. In the words of Blanca Elizarraraz, a mother from East Los Angeles, when describing her relationship with professionals:

> We're building a team that believes in each other, respects each other, trusts each other, and most of all values each other. We have formed "partnerships". We are partners who are providing a voice in the system; a voice we envision to be the true spirit of PL 99-457. We stand side by side advocating for the inclusion of all children with special needs in all areas of our lives. We advocate for change in a system which traditionally did not accept parents as key players on the "team". We advocate for services to be offered which reflect a family's needs and not just what's available. This is one heck of a team we are building! I'm proud of my partners and I know I can speak on their behalf, because we share a "vision"--that families will be accepted as effective members of the team.

References

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DEC Recommended Practices
Family Participation

Families are equal members in and can take part in all aspects of early intervention systems. This includes participation in all aspects of their child's care and all levels of decision making.

Program Advising/Policy Making

FP1. Family members receive payment for their expertise, time, and expenses while participating on councils, committees, and other aspects of early intervention policy/planning.

FP2. Meetings occur at times and locations that allow family members to participate.

FP3. Programs specify in writing, in an understandable manner, the roles of family members in program advising.

FP4. Program advising and policy making activities include members from more than one family.

FP5. Family members participate in the entire policy and procedures development process (from conceptualization through public comment and revision).

FP6. Families have the opportunity to develop policy making skills if they choose through mentoring and or training.

FP7. When it is necessary to use terminology (words or phrases) that are not familiar to family members, professionals explain the meaning of the terms in family-friendly language and provide written descriptions.

Staff Hiring, Training, Evaluation

FP8. Family members participate in and, if they choose, are paid for: developing job descriptions, advertising for positions, reviewing applications, interviewing candidates, selecting person for the job, conducting orientation activities for new staff, and evaluating staff.

FP9. Families may participate in a variety of roles in staff training: planner, needs assessor, deliverer, participant and evaluator.

FP10. Programs involve family members in gathering evaluative data and input from other families.

FP11. Evaluative feedback from and decision making with family members produces program changes, development, and expansion.

FP12. Family members help develop evaluation tools.

FP13. Family members have a role in the process of formulating conclusions and implications of evaluation data and in disseminating the results.

Family-to-Family Support

FP15. Family support services (respite, advocacy, parent-to-parent networking) are available as requested by the family.

FP16. Program personnel/staff introduce new families to other families in the program.

FP17. Family to family support services create an atmosphere which supports exchange of information among families.

FP18. Linkages to natural community supports for families are built and encouraged.

FP19. Support groups can include extended family members and other family support network members if a family chooses.

Intervention

FP20. Natural community settings are developed and accessible as an option for early intervention.

FP21. Family concerns, priorities, and preferred resources have priority in the determination of the instructional setting.

FP22. Program staff provide information to families about using intervention strategies across settings.

FP23. Families receive information when they ask for it in a way that is meaningful to them.

FP24. Families determine the pace of service delivery (e.g., to change intensity of child and family participation as needed to meet the family's needs).

FP25. Dreams and visions for the future expressed by families are encouraged and supported.

FP26. Families can initiate program monitoring activities if they choose.

FP27. Program staff explain methods of monitoring progress to families and offer options for modes of monitoring.

FP28. Families are asked to monitor progress and satisfaction to the extent they feel comfortable.

FP29. Essential supports such as child care and transportation are available so that families can participate in all levels of early intervention.

Interagency Collaboration-Meetings, Evaluation, Implementation

FP30. Families are included on all interagency teams and groups, throughout all phases of the effort.

FP31. Families are provided the opportunity and support to develop a handbook which helps them and subsequent parents through the "agency process."

FP32. Families are asked on an ongoing and systematic basis to provide feedback on the interagency collaboration process.

FP33. Agencies, with the help of families, develop one form which will be acceptable to all for intake, the IFSP/IEP, and monitoring.

FP34. Public awareness efforts are targeted at typical community settings to expand their availability to families of children with disabilities.

Legislative Issues

FP35. A mechanism exists to inform families about the importance of legislative involvement.

FP36. Families receive information in language they prefer and understand about the laws that support services to their children and themselves.

FP37. Professionals respect family members' decisions to become involved, or not involved, in political action.

Advocacy

FP38. Advocacy groups to support regular early childhood services include the concerns of children with special needs and their families.

FP39. Families participate equally (with professionals) in determining issues that are targeted for advocacy efforts by a program.

FP40. Professionals or agencies inform family members when they can not advocate for issues identified by families because of professional conflict.

FP41. Programs provide families with information on their State's advocacy services and organizations.

FP42. Veteran families support new families as they begin advocacy efforts.

Procedural Safeguard Development

FP43. Programs have clearly specified procedures for recourse/redress of grievances.

FP44. A mediator, independent from the program, participates in grievance procedures if they cannot be settled by the family members and the program.

FP45. Families may make decisions to use alternative services, programs, and methods unless they jeopardize their child's life.

Leadership Training Opportunities for Parents

FP46. Intervention programs coordinate training opportunities for families with parent training groups funded to provide such training as well as with other community training opportunities.

FP47. Families receive parent-directed newsletters and literature.

FP48. Programs provide support, financially if necessary, for families to attend local, state and national level meetings.

FP49. The program provides families with options for training opportunities, times, and methods from which to choose.

FP50. State lead agencies and ICCs fund an annual, formal leadership training for family members.